

**Department of Health and Human Services
National Institute of Environmental Health Sciences
National Cancer Institute**

**Minutes of the Research Translation, Dissemination, and Policy Implications
Subcommittee of the Interagency Breast Cancer and Environmental Research
Coordinating Committee**

May 2, 2011

The Research Translation, Dissemination, and Policy Implications (RTDPI) Subcommittee of the Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERCC) was convened for a meeting on May 2, 2011 at 1:00 PM EST via conference call. The Chair of the subcommittee was Jeanne Rizzo, R.N. of the Breast Cancer Fund.

Subcommittee Members Present

Beverly Canin

Karen Miller

Marcus Plescia, M.D., M.P.H.

Jeanne Rizzo, R.N.

Shelia Zahm, Sc.D.

NIH Staff Present

Christie Kaefer, M.B.A., R.D. (NCI)

Jennifer Collins, M.R. (NIEHS)

Liam O'Fallon, M.A. (NIEHS)

Guests

Galen Cole, Ph.D., M.P.H. (CDC)

Connie Engel, Ph.D. (Breast Cancer Fund)

I. BACKGROUND

The Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERCC) is a congressionally mandated body established by the National Institute of Environmental Health Sciences (NIEHS), in collaboration with the National Cancer Institute (NCI). This Committee is comprised of 19 voting members, including representatives of Federal agencies; non-federal scientists, physicians, and other health professionals from clinical, basic, and public health sciences; and advocates for individuals with breast cancer.

The Committee's primary mission is to facilitate the efficient and effective exchange of information on breast cancer research activities among the member agencies, and to advise the NIH and other Federal agencies in the solicitation of proposals for collaborative, multidisciplinary research, including proposals to further evaluate environmental and genomic factors that may be related to the etiology of breast cancer. The Committee serves as a forum and

assists in increasing public understanding of the member agencies' activities, programs, policies, and research, and in bringing important matters of interest forward for discussion.

The objectives of the RTDPI Subcommittee of the IBCERCC are integrated and dependent on the objectives and activities of the other Subcommittees of the IBCERCC and include the following: to identify successful models as well as gaps in research translation and dissemination, to make recommendations to improve both with an emphasis on breast cancer and the environment; to make policy recommendations to that end; to address areas in which the scientific evidence on breast cancer and the environment supports precautionary public health policy; and to identify methods to expand public participation in the research translation and dissemination processes to more effectively involve patient advocacy and community organizations, environmental health, environmental justice as well as practitioners in public health and health care delivery.

The fourth meeting (conference call) of the RTDPI Subcommittee took place on May 2, 2011. During this meeting, the May 12-13 meeting was discussed, along with the draft report outline for the goals the RDTPI is charged with addressing. The minutes from the April meeting were reviewed.

II. DISCUSSION

May 12-13 IBCERCC Meeting

The proposed template for the RDTPI presentation on May 12, 2011 to the IBCERCC was reviewed. Jeanne Rizzo will provide no more than a five minute review of the Subcommittee membership, its objectives, and the approach used for meeting these objectives. Jeanne asked that one member from each of the RDTPI teams deliver a ten minute presentation discussing their progress to date, preliminary recommendations, next steps, resources needed, and anticipated timeline for accomplishing its objectives. The presentation will include about 15 minutes for discussion. Beverly Canin will present for Team 1 and Marcus Plescia will present for Team 2.

Christie Kaefer is available to help prepare the RDTPI slides but will need input on the content from RDTPI members. Jennifer Collins prefers that the RDTPI Subcommittee provide a copy of its slides the day before the meeting; however, if last minute changes are anticipated, the presenters can bring the slides with them to the meeting on May 12th. However, if the RDTPI members want to provide any handouts, these materials will need to be submitted to Jenny by noon on Wednesday, May 11th.

An agenda for the breakout session on May 12th has been requested. Jeanne indicated she would like to rotate responsibilities for breakout session facilitation and report backs to the full IBCERCC for each day. Shelia volunteered to provide the report back on May 12th. A volunteer is still needed to help facilitate the breakout session on May 12th, and volunteers for both are still needed for May 13th. On May 13th, RDTPI members will continue to work on the chapter headings for the report.

Michele Forman is working on a definition of the term “environment” and ideas are also welcome for a definition of “innovation.” Additionally, the IBCERCC will need a working definition for the following terms: “translation” and “dissemination.”

Logistical issues related to the May 12-13, 2011 meeting were discussed briefly. For any travel-related questions, contact Kate Ryan at NIEHS.

Draft Outline

Team 1

Beverly and Karen reviewed Team 1’s outline, beginning with a discussion of the terms “translation” and “dissemination.” RDTPI members still need to work on their definitions of these terms; however, several members agreed the terms needed to be used together, even though they are different.

The outline will include examples of Federal and non-Federal models for translation and include discussion of key elements that make specific models successful, such as true collaboration between scientists and advocates. While the focus should be on models relevant to environmental research, other examples may be considered. Liam O’Fallon mentioned Team 1 may want to consider the draft NIEHS Partnerships for Environmental Public Health Evaluation Metrics Manual chapter that specifically addresses dissemination (<http://www.niehs.nih.gov/research/supported/programs/peph/materials/docs/chapter4.pdf>).

Barriers to successful research translation and dissemination will be discussed in the chapter. Jeanne felt that there may not be a sufficient number of trained advocates in the area of cancer and the environment available to work with researchers because the California Breast Cancer Research Program has a difficult time finding advocates who can serve as reviewers, but Karen disagreed and feels there are more individuals getting involved. Commonwealth received Stimulus funds to create an advocate training program, and Project Lead focuses on basic research. Shelia suggested this could be a policy recommendation.

Karen felt it would be beneficial to have a mechanism to “fast track” research questions, translation, and dissemination when there is sudden new evidence with the potential for immediate public health impact or is of high concern. She spoke to Ann Hernick about her experience disseminating a discovery immediately (before the science was published in a peer-reviewed journal) to families participating in a study conducted by the Cincinnati Breast Cancer and the Environment Research Center (BCERC), as well as Luz Claudio, Sabrina McCormick, and others. The Pediatric Environmental Health Specialty Units (PEHSU) are another model of interest (<http://www.atsdr.cdc.gov/emes/partners.html>) for building capacity among clinicians. The PEHSU help communities and populations affected by environmental exposures. They also have communication toolkits, write papers, develop continuing education programs for clinicians, etc.

RDTPI Subcommittee members discussed the tension that exists between the scientific need to publish research findings and the need to quickly share information with the public about environmental exposures. Shelia mentioned that most agencies want research findings vetted by

journals; research findings with an immediate impact can now be published more quickly through online versions of the journals.

Shelia also recommended that in addition to citing examples of advocate involvement in specific projects, it would be good to include some examples of advocate involvement in advisory boards for various federal agencies, along with other ways advocates can be involved in the research process. This may fit with the discussion of policies related to the conduct of research.

It was recommended that in Team 1's outline, the topic of radiation be moved to the section containing examples of research translation and dissemination and the topic of engaging communities be moved to the beginning of the document with the discussion of goals.

Team 2

The question was raised whether the topic of communication should continue to be linked to policy issues, or discuss in the report along with research translation and dissemination. Marcus forwarded a document from Galen Cole, Associate Director for Communication Science, Division of Cancer Prevention and Control, CDC that outlines their communications planning protocol (CDCynergy) as well as the key phases of the health communications process as described in NCI's Pink Book (Making Health Communications Work). Both of these two resources have been around for quite a while and could serve as the basis for a communications toolkit focused on environmental exposures and breast cancer. Jeanne recommended that this would be best done by those in the field of communications, but in addition to having the resources needed for the communications, it is important to make sure to "get it right" and that the "hard questions" are anticipated.

An example of past communication by the government that did not go well was the release of the U.S. Preventative Task Force's mammography guidelines in 2009. Galen commented that he spoke with someone involved with the guidelines and they said the main problem with the communications surrounding the guidelines was they did not test the messages with the recipients prior to their release.

Jeanne asked about the criteria for identifying whether a communication strategy and dissemination plan is needed. Galen indicated it really depends because the plans can range from simple to complex. Marcus added that in terms of environmental issues, many do not get communicated well. Jeanne also inquired about protocols for interagency communication. For the topic of breast cancer and the environment, Marcus did not know how well developed the communication channels are, and suggested the RDTPI Subcommittee may want to consider developing a recommendation for more formal pre-publication communication channels between agencies. Although communication strategies are in place, information may not be flowing optimally. Galen asked RDTPI members to consider whether they want to influence how information is communicated and/or who the information is communicated to?

Jeanne mentioned the group has identified that research findings are not really making their way to clinicians, policy makers, and the public. CDC's MMWR is one channel for disseminating information to the public, and is done using principles of health literacy. Jeanne referenced the

precautionary principle and the “right to know” approach, and in this context could be a RDTPI recommendation. Marcus thought he could draft some broad recommendations that apply to a range of agencies, and Jeanne thought the group could revisit this during the May 12-13 meeting in North Carolina.

(One RDTPI member shared an example of a recent Glamour magazine article on harmful chemicals in everyday products was provided: <http://www.glamour.com/health-fitness/2011/04/the-new-toxic-threats-to-womens-health>)

Shelia reviewed the document she prepared, “Why Policy Matters.” The key points included:

- Advancement of research is not sufficient to implement regulation or other actions to improve prevention, treatment, and diagnosis of cancer.
- Four categories of policy issues
 - Hazard identification
 - Risk assessment
 - Regulations
 - Policies related to the conduct of research, e.g. CBPR, setting research agendas, communication, training (need to clarify with Michael Gould’s Research Process Subcommittee whether they want to address this or if they want RDTPI Subcommittee to address)

Several existing reports, such as the WHO Asturias Pledge and the President’s Cancer Panel, have already made many clear recommendations. The RDTPI (and IBCERCC) can hone in on the portions of these reports relevant to breast cancer.

Action Items:

- Volunteer needed to facilitate the May 12th RDTPI breakout session.
- Volunteers needed to facilitate the May 13th RDTPI breakout session and also provide the report back to the full IBCERCC.
- Jeanne, Team 1, and Team 2 will finalize their slides for May 12th presentation.
- RDTPI Subcommittee members to review minutes from other IBCERCC Subcommittees to familiarize themselves with the issues they are discussing and planning to address in the IBCERCC report.
- Questions for other Subcommittees:
 - Does the Research Process Subcommittee want to address policy issues related to the conduct of research or do they want the RDTPI Subcommittee to cover the topic in the IBCERCC report?
 - What is existing science on radiation and breast cancer and what are the mandates for future research?
 - What is the mandate for research on intergenerational, early life, low-dose research as well as research on mixtures and interactions of environment with lifestyle, genetics and other factors?
 - How might chemical information from Confidential Business Information (CBI) such as for pesticides, inerts help us better understand the links between exposures and disease (breast cancer)?

- Do other IBCERCC Subcommittees (SOS, RP) conclude that there are sufficient/ or insufficient numbers of trained advocates on breast cancer and the environment?
- Think about possible definitions for key terms for the IBCERCC report: environment, innovation, translation, dissemination.
- Revisit topic of communication during one of the breakout sessions during the May 12-13 meeting. One possible topic: what are federal agency rules related to communication (and are they different from agency to agency). Some agencies are open to making scientists available to the media and others to discuss research findings; others have layers of folks who make it more difficult to access the scientists. The RTDPI Subcommittee is interested in knowing if there are formal protocols for this that differ from agency to agency. Sometimes the scientists are not available at all - agency heads, representatives, or communications staff issue statements and the process is very controlled.

III. ADJOURNMENT

The meeting adjourned at 4:00 on May 2, 2011.

CERTIFICATION

/Jeanne Rizzo/

Jeanne Rizzo, RN
Chairperson

Research Translation, Dissemination, and Policy Implications Subcommittee
Interagency Breast Cancer & Environmental Research Coordinating Committee

/Gwen W. Collman/

Gwen W. Collman, PhD

Executive Secretary

Research Process Subcommittee

Interagency Breast Cancer & Environmental Research Coordinating Committee

Proper signatures

Treat as signed, § 1.4(d)(2)